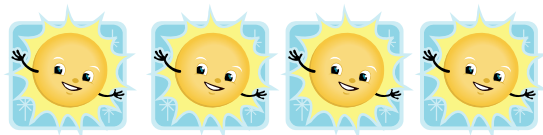


SPECIAL NEWS FOR SPECIAL NEEDS

Summer 2006



Hello, Summer! May your days be warm, your breezes steady, yet mild and your humidity low!

With the season, come new opportunities for you and your children. We encourage you to look at the local community events section of your newspaper for fun, interesting and many times; my favorite, FREE events.

For instance, check out our upcoming Family Forums or Parenting class. Or, refer to organizations such as the Sussex Family Network, Parent Information Center, Autism Society of Delaware or your local libraries for events and resources that will grow your child's mind!

Enjoy a picnic at a park, a day at the beach or an evening at the Delaware State Fair. Ask your child what he or she wants to do . . . you've got the whole summer ahead of you!

Kellie McKeefery and Jennifer Donahue

Family Support Specialists

Kellie (302) 995-8617 kellie.mckeefery@state.de.us

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Sussex Family Network

By: Jen Pulcinella

Do you sometimes feel like you are the only family around who has a child with special needs? Are you frustrated because resources can be hard to find? Do you wish you knew another family facing the same challenges?

You are not alone. There are over 400 children, under 3 years old, in Sussex County receiving services from the Birth to Three Early Intervention Program. The Sussex Family Network wants to connect these families for the purposes of providing support, sharing resources and lending a friendly ear.

Join us for a day loaded with fun for the entire family. Celebrate the launch of The Sussex Family Network with Sussex Family Fun Day at Trap Pond in Laurel, DE on June 24th from 9AM-3 PM. For directions, call: 302-875-5153. Or on the web, go to:

<http://www.destateparks.com/tpsp/tpspmap.htm>

*Volunteers are needed June 24th from 8AM-4PM, to help with activities and entertainment. Feel free to contact us at SussexFamilies@aol.com to see how you can help or if you have any questions. *

Parenting Class

The six-week Parenting Series featuring Yvonne Naas, a family educator, is being offered on consecutive Wednesdays to families of children with special needs starting July 26, 2006. Sponsored by Parent Information Center, this series will include segments on behavior, discipline, coping with stress, self-esteem and parenting skills. Each session runs from 6:00 p.m. to 8:00 p.m. at Easter Seals in Georgetown. Registration is required and on a first come basis; there is no charge. If the cost of childcare is a concern, please mention upon registration. Call Jennifer Donahue-Sawchenko (302) 424-7345 for more information; feel free to leave a message.



Special News for Special Needs
Delaware Health & Social Services, Child Development Watch, Summer 2006



Do You Want to Help Your Child Become A Better Communicator?

Then join us for an information session about
It Takes Two To Talk

Wanted:

Family members or caregivers of children with language delays; anyone who wants to help their child to better connect with their world!

Where & When:

New Castle County
Wednesday June 28th AI Dupont Hospital 6:30pm
Or
Wednesday July 5th at Easter Seals in NCC 6:30pm

It Takes Two To Talk is a family-focused program based on years of research into how families communicate with their children and how the communication skills of children with language delays can improve with their families' help.

How Does the Program Work?

It Takes Two to Talk was developed by the world-renown Hanen Centre. This program uses a speech language pathologist to assist you in learning and using simple strategies to help your child become a better communicator through everyday activities.

If you have Questions. . .Call Ron Engard at (302) 998-2543 ext. 298 or Carol Ann Schumann at (302) 255-9136 or ask your service coordinator for more information. If you cannot make the first session of the program, please call us. We want to help you help your child to make a strong connection with his or her world!

A Call to All Families

By Michelle Lamers

Calling all families to learn about New Scripts!

Who are we and what do we do? We are a group of families and professionals who work together to make a difference for the children of Delaware. New Scripts originally developed from a grant and continues to exist through funding and determination. Families of children with disabilities work closely with professionals to teach people what everyday life is like for our families. Through our unique experiences, we have many opportunities to influence the attitudes and practices of the people who work with our children, now and in the future.

We want the help of families like you in all of Delaware's counties. If you or someone you know may be interested in joining, I am always glad to discuss New Scripts; feel free to contact me at one of the numbers below or by email.



DELAWARE
New Scripts

Michelle Lamers
Coordinator
Phone: (302) 999-7394
Fax: (302) 999-7637
Toll Free: (888) 547-4412
Email: lamersmm@aol.com

"Embedding the family voice in all aspects of early childhood intervention"

Speech News

By Michelle Blankenship, M.S. CCC-SLP

- "Children do not learn to talk all by themselves. They learn language by listening to and interacting with others, and through involvement with their world. For some children, learning to communicate does not come easily. Sometimes the reason for these difficulties is obvious; other times it is less clear."

—www.Hanen.org

The above quote gives families a lot to think about. Fortunately, early intervention for children with language delays has proven to work very well. Since families are the most important people in a child's life, their involvement in this process is most important.

Speech-Language Pathologists provide treatment in many settings for children who have difficulty communicating. Our goal is to empower families with the natural learning opportunities that happen in daily life. With some guidance, a night-time bath can be changed into a language-rich activity and getting dressed can be an experience full of comments, requests, labels and fun. Brushing teeth can be a "face-wake-up" alerting the mouth and leading to new movements and sometimes, new sounds.

There is a great need for speech/language pathologists in Delaware. The shortage of these professionals will be addressed with the creation of a task force enacted by Governor Minner's 84th Executive Order. The task force is the first step in raising awareness and moving forward to a solution to meet the needs of the families in our communities.

Communication is the key to the human spirit. Whether it is a word, a sign, a gesture, or even just "that look" – it is our connection and the basis of the bond we have with our children and each other.



Joining Generations

By Carol Boyer

We used to imagine grandparents as elderly folks who gave treats and love to visiting grandchildren— then packed them up and sent them back home with mom and dad. These days, that notion is history! We have a new type of family that we refer to as “grand families.” This term is applied to those families in which grandparents or great grandparents are raising the child or children of another relative.

Tiny Delaware contains the 14th largest population of grand families in the United States; there are about 8,524 grand families in Delaware caring for 13,700 children! What might Joining Generations offer for you?

For starters, Delaware has two laws specifically geared to relative caregivers. These laws allow the caregiver to approve medical treatment and to register children for school.

The Joining Generations program, located in the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), offers programs and information assistance through the following:

- Grandparent/Relative Caregiver Information and Support groups- for locations, dates and times refer to the website and call the sponsoring agency for confirmation.
- Kinship Care Program– provides funds for transitioning children into their Grand Family. Contact your nearest State Service Center or call the Delaware Help Line at 1-800- 464-4357.
- Resources- printed and electronic documents are available via the web address listed below, under “Publications & Forms.”
- Camp Respite – summer and school break day camp; contact your local YMCA and/or Boys & Girls Club.
- *Grand Time Off – provides limited subsidized childcare; contact The Family & Workplace Connection at 1-800-537-5557.

*Caregivers must be 60 years of age and raising a relative’s child. Grand Time Off has some funding for caregivers age 50 to 59.

For more information about the services offered by Joining Generations, visit the DSAAPD website at www.dsaapd.com. Click on Caregiver Information & Support and then click on Intergenerational Programs on the left side bar. You may also send questions via e-mail to DSAAPDinfo@state.de.us or call Joining Generations at: 1-800-223-9074.



Autism Registration and Surveillance

The Autism Society of Delaware was the driving force to pass legislation to create a registry of information about the prevalence of autism spectrum disorders in the state of Delaware. The law required Delaware to establish and maintain an autism surveillance system and registry for children from birth through age 17. The Division of Public Health has established this autism registry and surveillance system.

What does the autism registry do?

The registry collects information on diagnoses of autism spectrum disorders for children from birth through age 17. Qualifying individuals are included in the registry after their diagnoses are reported by doctors, other health care practitioners, hospitals, and clinics. Reportable diagnoses are those used by the International Classification of Diseases (ICD) that is used by the CDC; the Pediatric Association system (BPA/ICD-9), or the Diagnostic and Statistical Manual of Mental Disorders (DSM IV).

Is reporting required?

Yes. Reporting is required by any health professional who diagnoses a child with autism spectrum disorder. In some cases the person providing care for the child is not the person who initially diagnosed the child. In these cases the health care professional providing care would be required to report. Annual follow-up reporting is also required to keep the registry accurate.

Is this information confidential?

Yes, the data is entered into a registry that is accessed by the Newborn Screening Program personnel only.

What will the law do for you?

The registry gathers information to track changes in prevalence over time, to inform the planning of service delivery for children with autism and their families and to facilitate autism research. With accurate reporting this registry may provide information for better planning for children and adults with autism in Delaware.

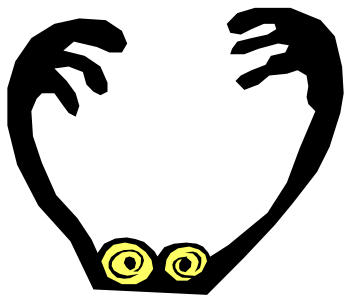
What can families do?

This law is supported by many advocacy organizations for persons with disabilities. An accurate and continuing source of data about autism is important. Families can facilitate reporting by bringing the form to their health care provider and encouraging submission.

The form is available to download through this link: <http://www.dhss.delaware.gov/dph/chca/dphnsp7.html>.

For questions, please call:

Mary Carroll McCaffrey, Newborn Screening Program, 302-741-2990



Taming the Paper Monster

By Beth Andersen

When my son, Nikolas, was born 2 ½ years ago, I'd no idea I'd have to deal with so many different specialists, therapists, service coordinators, etc. As time goes by and Nik accumulates more diagnoses and requires multiple therapies, the volume of paper I have to deal with increases daily. IFSP's, medical reports, therapy notes, referrals, prescriptions, articles of interest, catalogs of specialty items—the list seems endless. It is not an exaggeration to say the stack of papers is as tall as, if not taller than, my son who is 2 ½ feet tall!

As we get ready to transition out of early intervention and into the school system, I realize that I'll no longer have the benefit of a service coordinator to help me keep track of all the little bits and pieces of information about my son's needs and care. I'll become the sole keeper of all of Nik's "stuff" and I need to get organized.

While the idea of having to sort through a mountain of papers to organize them all is daunting, it's even more stressful to need something as simple as an old medical report, for example, and to have to sift through stack and stacks of paper to try to find it to provide to a new doctor. I finally realized that finding a way to stay on top of all the extra papers is not only a good way for me to stay on top of my son's care, but it can also help alleviate some of the day to day stress that I feel. As I embark on my own version of "spring cleaning," I thought I'd share some of what I have learned.

First, there is no right or wrong way to organize the information. The most important thing is that you organize it in whatever way makes it easy for you to find the information you need when you need it. There are any number of web sites available to provide guidance, and sometimes even entire forms, for ways to organize your child's care information into a logical, even portable, format so you always have what you need to communicate vital information to your child's care providers, specialists, or in case of emergency. For me, it is one of the things I'd take with me if my house caught on fire.

Taming the Paper Monster, continued...

Second, you don't have to do it all alone. This is the perfect task to ask someone to help you tackle. It could be your mother, your best friend, your spouse, or even your older kids. Just put on a pot of coffee, tea, or whatever might make it feel more like a social occasion and invite someone over. Having company makes the time go faster and the job less overwhelming. So the next time someone asks, "How can I help?" you've got just the answer!

Third, don't try to do it all at once. The old saying about "eating the elephant one bite at a time" is true. Every little bit makes a difference. It could be as simple as taking the first step to figure out what sort of system will work for you. Next, gather any supplies you may need such as file folders or notebooks—whatever it might be. Bit by bit, you can break the job into smaller parts and do whatever you feel up to.

Finally, you have to use the system for it to work! Sometimes, it feels simpler to just let the papers start to pile up, but if you take even a few minutes a day to just put them in their newly-created proper place, you won't ever have to think about them again—well, at least until you need them for something. Then, you'll know exactly where to find them.

By the way, I'm still gathering my supplies. Want to come over for coffee?



Useful Internet Sites:

- The Center for Children with Special Needs (through Children's Hospital & Regional Medical Center in Seattle, Washington) at <http://www.cshcn.org/resources/CareNtbk.cfm>
- The Jean Baton Swindells Resource Center for Children and Families, a part of the Providence Health System in Portland, Oregon at http://www.providence.org/Oregon/programs_and_services/childcenter/e15swindells.htm

If you don't have access to the Internet, you can contact either of the hospitals above. They will, for a nominal fee, mail a copy of their "care notebook" to you. You might also ask your service coordinator for suggestions.